Initiative on "Caring Through the End" February 2005

CMS is committed to the quality of care its Medicare beneficiaries receive through the continuum of care – beginning to end. As such, CMS has undertaken a number of initiatives to encourage beneficiaries to be active participants in their health care and to make informed health care decisions. In 2000, the Renal Physicians Association released "Shared Decision Making: the Appropriate Initiation and Withdrawal from Dialysis." Despite recommendations for active decision-making, there is an apparent lack of accurate information available to dialysis patients to inform, and assist, them with the health care choices they need to make at the end stages of their life. Further, when patients have made choices, their wishes are not always respected. For example, it has been noted that in many cases when patients have elected to not receive CPR should they go into cardiac arrest during dialysis, their wishes were ignored.

In response to this lack of information, CMS, through the Mid-Atlantic Renal Coalition (ESRD Network 5), held a conference that examined the care of dialysis patients through the end of life. From the experiences and expertise of the conference participants, and follow-up discussions with technical experts in the field, manuals and training materials for professional caregivers will be developed encouraging them to talk to their patients about the health care choices that need to be made during the full continuum of care, including the hard choices at the end of the continuum. The goal is to have the care that is provided be the care that the patient wants, and be the best care for the patient's unique situation. Once the educational materials are developed, they will be used nationally by the ESRD Network Organizations to educate dialysis providers on end-of-life care and decisions. In addition, the ESRD Networks will conduct educational sessions for dialysis providers on medical, ethical, legal, and practical issues surrounding CPR in the dialysis unit.